

**People Leading Accessible Networks of Support (PLANS)
Family Support 360
Statewide Workgroup
Radisson Hotel
Rapid City, SD
March 10th & 11th 2005**

CALL TO ORDER

Clint Waara called the meeting to order at 2:30 p.m. MDT on Thursday, March 10, 2005.



Members Present were:

Travis Arneson	Clint Waara	Julie Carpenter
Ronda Williams	Kristen Blaschke	Brenda Smith
Kirby Mellegard	Linda Daughters	Ted Williams
Beth Hosek	Cindy Taber	Dan Spotted Eagle
Dawn Kellogg	Mary Funge	Sharon Sonnenschein
Kristi Heumiller	Vikki Day	Jennifer Seale
Tim Neyhart	Renee Osborne	

Others Present were:

Brooke Lusk	Lisa Lunstra	Wanda Seiler
Tarra Stoesser	Arlene Poncelet	Yvonne Reynolds
Kristen Kiner	Kris Kileas	Dennis Popp
Norm Jerke	Tom Schienost	Gloria Pearson
Julie Johnson	Daryl Kilstrom	

Introductions and Update

- Staff Update – Deb Petersen, Division of Developmental Disabilities, will be the new Project Director for PLANS. Refer to the contact sheet in your binder for staff information.

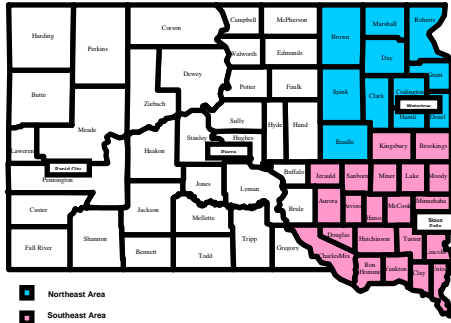
GRDDSS Update – Renee Osborne

- Brooke and Lisa have been to Milbank frequently in the last year. Locally, as a group they have grown. They have melded and become more organized and have tried hard to work with the school districts.
- GRDDSS received funds from the Milbank area Combined Appeal. In the first quarter, funds were used for individuals who use the recreational center.
- Most recently, GRDDSS has brainstormed job ideas for people. It seems as though there are more jobs than there are people.

- GRDDSS is trying to think outside the box – bigger and broader.
- Discussed the possibility of having a representative from each of the eleven counties meet quarterly with the Northeast PLANS Coordinator to keep the lines of communication open.

Comment from Wanda: GRDDSS was the one of the seeds that really helped start the initial PLANS project.

People Leading Accessible Networks of Support (PLANS)



Progress of Local Programs – Brooke Lusk Southeast Area

- It has been really great to start the implementation plan in the state.
- For the Southeast program, we chose a fiscal agent, the Mitchell Adjustment Training Center. The fiscal agent is responsible for employing the PLANS Coordinator and cutting checks for the services and supplies, etc. that are needed by those accessing the PLANS Project.
- Received 40 to 45 applicants for the Southeast PLANS Coordinator position.
- Kristin Kiner was hired and her office is located at the SD Career Center in Sioux Falls. She is busy making lots of connections.
- We have been getting many referrals for people interested in PLANS. We have had to start discussions about prioritizing needs for people.
- Each program will serve approximately 40 people.

Southeast PLANS Coordinator - Kristin Kiner

- Has met with 13 people who are interested in receiving services through the PLANS grant.
- Already has a lot of successes and emotional moments.
- Has met with 6 Family Support coordinators from the southeast portion of the state to identify people who may want to access PLANS.



- Success stories:
 - 1) Help with setting up providers and purchasing services. New item found: due to health concerns a woman spends most of her time in

her bed and bedroom. She really wants to “splash” around in a bath. Found an inflatable bathing system that can be rolled underneath her in her bed. Two hoses are attached, one brings in water, one pumps out water and now she can splash around in her bed and truly enjoy it!

- 2) Someone wanted to move because they felt they didn’t have a lot of friends. Kristin met with them and they discussed options and she gave them information about what is available in SD. By the end of the meeting they all felt they had more information and were more comfortable with their choices and communities.

Progress of Local Programs continued – Brooke Lusk Northeast Area

- Approached a little differently than the Southeast area. A Request for Proposals was developed with GRDDSS and then a panel reviewed the applications. Huron Center for Independence was chosen as fiscal agent.
- Huron received 31 applications and interviews were completed last week.
- They hope to hire someone next week so that services can begin in April 2005.

Comment from Deb Petersen: It is great to have Kristin on board and out there working in the communities!

Question from Dawn: You said you can serve a maximum number of individuals in each area – if you don’t have 40 in an area and more in another area can we appropriate services to accommodate this?

Brooke: This is something we are going to definitely discuss and possibly adjust and balance for in the future.

Kirby-Were MOU’s (Memorandum of Understanding) needed for any of this or will you be developing them?

Brooke: At this time we haven’t had to use one because it hasn’t been an issue. Agencies are stepping forward with the necessary services and assistance.

Break



Provider Sub-committee report – Brooke Lusk and Dawn Kellogg

- Going back to the October provider meeting– Dawn, Danny, Cindy, Beth and Brenda all spoke and told a little bit about themselves and their involvement with PLANS.
- They asked the providers to challenge themselves and discuss the 10 issue items developed at the October meeting. The providers came up with some of the same ideas that the PLANS group has had.
- See handout “Formulating a Vision for the Future” from the provider meeting held in October. Dawn went over the key points under each topic.
- The sub-committee felt this was a great start, but that more time is needed to address these issues.
- Therefore the provider sub-committee is going to meet each time the PLANS workgroup meets. They met “face-to-face” for the first time right before this PLANS meeting, however they did have an assignment that they were sent via email due to the January meeting being cancelled.
- The sub-committee split into groups and began discussing the issue items and developing goals, objectives and tasks for each item. Brooke and Dawn went over the goals that were developed and put forth during the sub-committee provider group. **(see goals from sub-committee minutes)**.
- We will share information as the sub-committee progresses.

TASH Conference – Brenda Smith

- The conference was held in Reno, Nevada this year.
- Advocates for and promotes self-determination for people with disabilities.
- A lot of the conference focused on self-determination, employment, and person-centered supports.
- Self-determination is a philosophy. People should have the freedom to choose. Those things that are part of self-determination are as follows:
- Authority – individual budgets.
- Autonomy – building on natural supports.
- Responsibility – with choice comes responsibility and accountability.
- Personal support agent – (as it is called by some states) My support person might be different than your support person.
- Fiscal intermediary – funds go into an account for you and they manage this for you.
- One session Brenda found particularly interesting was from a group in Ohio who spoke about creating book clubs. These book clubs are for people of different stages of literacy and they get out and socialize with each other no matter what level of literacy they are at in their lives.
- Another session/issue that Brenda found interesting is the arts. What are those things that bring you joy? Some people have started businesses revolving around art and their creativity!
- Human Services Resource Institute started a newsletter – The Riot! – covers areas that are of interest. Can be found online. www.hsri.org

- Sometimes we are so focused on gaining skills that we forget about developing the creative part of a person's life.
- Al Condeluci will be presenting in Sioux Falls. How do we build and create atmospheres for everybody. He focuses on community and interdependence. He teaches people how to be brick builders and relate to people in their communities. Spread the word!!!

PLANS forms – Brooke Lusk and Deb Petersen

- Brooke outlined the different forms that have been developed/amended.
- The forms are not available on-line at this time but the application and the directions for the application will definitely be available on the PLANS website. The other documents will probably only be needed by the provider or fiscal agent.
- Brooke will email everyone the PLANS brochure and would like suggestions and comments.

Rights Training – Deb Petersen – (refer to handouts)

- Decision Tree Scenarios.
- Tool is intended to promote team discussion regarding individual rights.
- Tool assures due process.
- Rights Scenario handout for Helen

Group Input

Danny: Why don't you give her a cell phone or get her friend's number and call every couple of hours to make sure that she is okay and everything is going well. That way she has her space and the provider/parent feels comfortable.

Ted: Is this considered a limitation? I used the decision tree and quickly came to a conclusion. This could be argued several different ways. Is it really considered a limitation?

- What it really boils down to: "Is it a right's restriction?"
- Education is knowledge!
- You can't restrict unless it is life threatening or an emergency.

Group Input

Kris Killeas: We do use the Rights Tree at our agency and we have certain criteria that if met, we do consider restrictions. It has actually been a valuable tool.

Linda Daughters: Hasn't incorporated the right's document into their agency, but they are considering it. The clients have the privilege to speak out about what they want and what they consider their rights.

Travis: The one that says can't restrict unless it is an emergency or life-threatening – isn't that open to a lot of interpretations?

Answer: Use common sense scenarios – can they get hit by a car crossing the street?

- Dignity of Risk- we take risk all the time like when we cross the street or drive too fast.
- What's the worst thing that could happen if we take that risk? This should be considered.
- Rights Test (refer to handout)
- Due Process - The team needs to involve the person!
- Various counselors, lawyers and advocates can and usually are involved in the Human Rights Committee.
- Elements that need to go into the restoration plan:
 - The plan needs to be tailored to that person
 - Has to be measurable
 - Has to be time-limited.

Housing Update – Tim Neyhart



- If the information you've received so far seems disjointed – it is.
- This is a group of people who got together after the conference last fall and liked the ideas that were brought up.
- The group gets together quarterly and has discussions regarding how to get this started.
- Arlene, Julie Johnson and Lisa Lunstra have been a part of this from the beginning.
- Any kind of gift or unearned income can affect funding. Big issue is developing down payments – no one can gift you the money, etc.
- A trust is a viable option. You can put money in a pool trust and it won't affect your SSI funding. There are a couple of pool trusts in SD.
- When we started we thought we were going to have to revamp the system, but after all our research, we discovered numerous possibilities in SD!
- NESCAP Northeast Community Action Programs – they will match funding. It is an individual development account.
- There is one in Pine Ridge – probably have to be a tribal member.
- If person on SSI does get in a home ownership issue- what happens to that equity when the person passes away? This is an issue that we are dealing with.
- Tried to design so home ownership and home rental are equal – 30% of their income.

Questions and Answers

Travis: If you rent, you aren't responsible for maintenance and all of that. You also know you won't pass anything on. By owning it, you have to put forth more effort for yardcare etc. but you also know you will pass something on. Why would anyone want to take care of all of that if they won't get anything out of it in the end?

Answer: The people who will take advantage of this are a small number. The people on SSI who will be eligible are very few. He advises that individuals look at these variables and issues if they are considering this option. Maybe for a lot of people these hassles aren't worth it!

Vicky: Why couldn't your family put your money in a trust fund for you?

Answer: It may be possible to do this.

Sharon: SSI and Medicaid each have rules. They are pretty strong about their transfer policy and the rules are getting stronger. There is a clause in every one of those trusts that says the state must be paid back after the person passes away. There are different rules/safeguards for people with disabilities. If there is a spouse, the house should be in the spouse's name also, so that they have partial ownership. Medicaid will not take over a house if a spouse or dependent is in the house (at least not right away).

Tim: There are things to be done in this area!

Danny: How can you pay them back if the person is passed on?

Answer: Through the estate process. When people die, they leave an estate and if nobody has a claim on it then Medicaid can claim it.

Wanda: If I'm a home owner in this situation, can I sell my house to get a better one.

Answer: You can sell your house to build equity. There are some restrictions, such as 6 months to buy after selling.

Food Stamp Update – Lisa Lunstra

- In January, statistics show the highest applicants ever for food stamps.
- Do believe a lot of people are eligible who haven't applied.
- There is a new application process for people living in small group homes. How does PLANS relate? We obviously have a lot of SSI recipients who may be eligible.
- Kris Killeas- it is an advantage of time. Reapplying doesn't have to happen so often, which is an advantage.

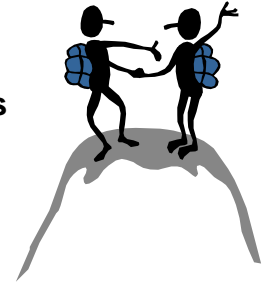
Wanda: I think we are talking about two separate projects.

Sharon: Yes, one hasn't started yet. So far the feds are saying that people of households eat together. If you move that philosophy to a group home, this affects the home. This project will affect more of the elderly population too, because they are looking for single households for eligibility.

2005 Disability Summit- Many Voices, One Vision – Bob Gettings Conference Call

www.allianceforfullparticipation.org

- Thanks to the PLANS workgroup for doing what you do!
- History – 1999-2000 there were a group of national organizations that became concerned. We came together and formed a coalition. Decided maybe it was time we all come together in the interest of developmental disabilities and develop a broad national agenda to move forward. At this time (late 2002) they formed the “Alliance for Full Participation” and the summit conference was born.
- National Summit will be held in Washington D.C. September 21st – 24th 2005.
- The idea is for different stakeholders to all come together.
- Working very hard to identify scholarship money for self-advocates.
- Fortunate to have direct support professionals involved.
- Center of Disease Control and Prevention has put several thousand dollars into the Summit as have other sponsors.



Group Input: Questions and Answers

Brooke: Is there a timeframe for notification of applicants who have submitted applications for proposals of breakout sessions or posters?

Answer: They have over 300 proposals. The moderator is really the one responsible for making the selection of who gets to attend the session. It will probably be May or so before they will notify panelists.

Brooke: When can we expect an agenda of sessions?

Answer: We have an agenda that is in draft form. There are a couple of keynote speakers who haven't been addressed/accepted yet. They hope to have an official agenda/conference book out soon, no more than two weeks.

Kirby: If a family member wanted to attend this conference, what specific action should he take? Is there reading that should be done, stories to be told, etc?

Answer: There is a website available and listed above.

Brooke: DD council has approved funds to send some individuals to the conference. We are looking into other possibilities for funding.



Break into three small groups to go over the bulleted items on the suggested discussion guide from the Alliance of Full Participation. (Refer to handout)



Successes

L2 – How can grass roots alliances be established or expanded at the local level to assist individuals with lifelong disabilities to become valued, contributing members of the communities in which they live; and what opportunities to build such alliances exist (or could be created) within our state?

- PLANS is addressing

L5 – What steps can be taken to attract a dynamic, new generation of public servants to replace experienced federal, state and local administrators who are leaving public service at an accelerating pace, thus creating a yawning leadership void; and what are we doing in our state to address this rapidly growing problem? Similarly, how do we attract and nurture the next generation of self advocate and service provider leaders?

- Training for College of Direct Support (CDS), Partners In Policy (PIP), Youth Leadership Forum – start building on this

C1 – How can we best promote effective, innovative approaches to assisting children and adults with disabilities to establish enduring connections to the community, including developing long-term friendships and intimate relationships; and, what actions can be taken in our state to ensure that strong community ties are established by individuals with lifelong disabilities?

- PLANS, Family Support Council, adjustment training center's Evolving - room for improvement

C4 – How do we ensure that the basic foundational supports are in place within communities across our state to allow individuals with lifelong disabilities to control their own lives and direct their own supports?

- PLANS Workgroup

C8 – How do existing community service provider organizations and public entities need to change in order to adapt to the growing demand for self-directed, individualized services; and, what steps are being taken within our state to help provider organizations and public entities to successfully navigate this change process that ensures free choice of provider and eliminates conflicts of interest of all state Medicaid authorities of providing direct supports.

- PLANS, Pathways, GRDDSS and Resource Coordinators moving in this direction

E4 – What balance should be struck between self-direction and assuring that vulnerable individuals with disabilities are not exposed to unacceptable risks; and what efforts are underway within our state to develop and institute improved risk management strategies?

- Awareness, rights training, Person Centered Planning (PCP) and better education for siblings

E6 – What steps need to be taken in our state to improve the core competencies of direct support professionals?

- College of Direct Support

E7 – How can private provider agencies create a cultural of quality within their respective organizations; and what steps are being taken within our state to promote the development of such quality oriented provider organizations?

- Council returned to state – mechanism to access and improve quality – all agencies accredited within 2 years

E8 – What additional actions need to be taken in our state to ensure prompt access to needed services and supports, thereby eliminating service waiting lists? What actions can be taken to address the growing inequity between those who receive paid services and those who do not?

- Minimal waiting list



Challenges

L2 – How can grass roots alliances be established or expanded at the local level to assist individuals with lifelong disabilities to become valued, contributing members of the communities in which they live; and what opportunities to build such alliances exist (or could be created) within our state?

- DD Council – fund self-advocates - build on what we have – how to bring people in not receiving services from ATC?

L5 – What steps can be taken to attract a dynamic, new generation of public servants to replace experienced federal, state and local administrators who are leaving public service at an accelerating pace, thus creating a yawning leadership void; and what are we doing in our state to address this rapidly growing problem? Similarly, how do we attract and nurture the next generation of self advocate and service provider leaders?

- Some things in place in individual agencies, but still building on

***C2** – What steps can be taken in our state to ensure that children and adolescents with disabilities make a smooth transition to adult life, including possible improvements in secondary and post-secondary education and career training programs?

- Transition tough – don't know if we've been successful - how IEP can be different if we have a Resource Coordinator or Advocacy attending, enforcement of IEP - breakdown of resources in education regarding adult services

C3 – What actions need to be taken in our state to ensure universal access to essential community services, including housing, medical and dental care and social supports, regardless of the individual's age, the level support required and the special challenges faced by such persons?

- Transportation, housing, dental care, mental health and lack of collaboration between medical staff

C5 – What actions need to be taken within our state to ensure that adolescents and adults with developmental disabilities receive the individually tailored training and supports they require to be employed in fully integrated work settings?

- Jobs very important; educating employers on benefits of support system available

C6 – What steps need to be taken in our state to remove legal barriers to the full participation of persons with disabilities in American society, including protections within the criminal justice system (as a victim, alleged perpetrator or witness to a crime), guardianship, marriage, child custody, etc.

- Indicating borderline eligibility; sex offenders; plan for future guardianship; advocacy; not involved much with testifying issues

***E2** – What strategies for recruiting and retaining a highly qualified frontline workforce, including direct support workers, educators, health and allied health professionals, etc., have proven to be effective; and what actions need to be taken in our state to initiate or accelerate the use of such techniques?

- Beyond Direct Service Professional (DSP) expand to educators and Health – turnover - recruitment and retention, making staff aware of needs, person always training new staff

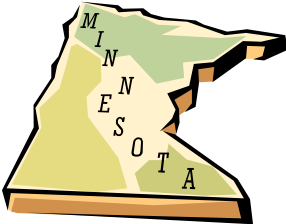
E3 – How can quality assurance and performance measurement systems contribute to improving the quality of supports furnished to children and adults with developmental disabilities and their families; and what is being done in our state to adopt or promote the expanded use of such quality assurance/quality improvement systems?

- Council sees this as a weakness in SD - putting preventative measures in place – becoming proactive vs. reactive

Group input:

Julie Johnson: Just a comment I would like to make, you're not going to access things that you are not aware of!

Wanda: I believe within the next two years all of our agencies will be accredited by the Council.

**Minnesota HCBS Information – Laura Doyle, Minnesota****DHS – conference call (refer to handout)**

- Laura Doyle – MN Dept of Human Services. Worked in this field for years also a parent of a 35 year old young man with disabilities.
- Have a family support grant that they use in MN
- Criteria really limited to quality assurance measures.
- Wanted to allow people to have more family support options.
- By 2001 10 counties of 87 counties participating, six months later 18 counties participated. As of last year, 36 counties participate.
- One problem that they have is what is allowable. What may be allowable in one county, may not be allowable in another.
- Their division has 4 major waivers that they use.

Travis: If they don't like the budget, can they appeal.

Answer: In MN, anyone can appeal anything, but they won't win the appeal.

They can choose to go back to regular funded waiver, but their budget won't change. There can be a change made upon change of needs.

- New amendment became effective October of this year.

Question from Laura: Do you have anything similar to this in SD?

Answer: There is really no entity in SD acting in this pure fiscal agent capacity at this time.

- Biggest barrier is finding something usable and viable.
- The county still has activities that they have to perform to meet federal requirements.
- They used the structure they already have to address the quality assurance issues that they have.

Question about guardianship and substitute decision making.

Answer: One of things that is a requirement is the assessment for the need for any kind of decision making. MN has a public guardianship system in place.

Question: What role does the provider/family member/advocate play in self-directed services that you have?

Answer: At the age of 18 you are considered to be an adult and capable of making your own decisions, unless you have a legal piece of paper stating otherwise. A person has to have legal authority in order to make a decision for you.

- Budget development was very technical.
- Used research scientists who had some very specific and intensive statistical abilities to develop budget methodology.
- Process took a little over a year to build the formula.
- Based upon number of people that are not receiving consumer driven support.
- For the hospital and medical waiver r^2 was .713 and for MR/DD waiver r^2 was .559.
- They have an ongoing workgroup that examines what they have done and the flaws.
- Also have a group working with data mining. They've had a lot of complaints with the budget methodology.
- Get a lot of value judgments from the county level.
- Can't do a really good job based on the variants that you see in the document.
- Biggest issue in budget methodology - the inequitable treatment of individuals. Need to access more money for the right individual. Really want to achieve statewide equitability for people.



Question from Travis: If you could set the budget again, how would you go about it?

Answer: She wouldn't change what they did, but she would change the assessment tool that was used.

Question from Ted: Did you use a self-developed tool or standard assessments?

Answer: Used from people within the state but it is standardized.

- Didn't actually expect to save money but state set budget and not the county.
- Another unpopular factor.

Question from Kirby – Do people who remain on regular waiver program, does their cost go up and does the legislature give you grief about that?

Answer: No, the people with the highest needs use it and are very interested in using it! Very interested in continuity of services.

Kirby: is there a cap on what people can receive for community based services?

Answer: May be higher than what people actually receive, but sometimes lower. They are using a standardized tool.

- Spent a lot of time developing brochures and did very extensive training.
- Have a consumer manual online and a lot of other tools online for consumers.
- If you can do it clean and learn from others mistakes, it is much easier to do!!

Question from Wanda: in terms of securing your waiver amendment how painful was that process.

Answer: We started in 2001 and got final approval last March (2004). We went through a series of conference calls and spoke with CMS and other agencies repeatedly. Very difficult to do this and it took a lot of hours. Had to take it to higher ups and it went on for quite a long time. If questions, they would be able to send you what they did in MN.

- Brooke will send out the website so workgroup can review the documents that Laura introduced.
- Laura would like to be updated with our project progress.

Quality Initiatives – Wanda Seiler (refer to handout “What is Quality”)

- The methodology we use to budget in SD is similar to the method in MN.
- Quality is defined differently by different people

Path plan

Break into small groups – work on tasks and objectives

Group Input:

- As far as the Path map-thought that it contained a lot of info and obviously took a lot of work. It didn't necessarily make sense when you weren't involved in the process.
- They don't feel they need to revisit or remap plan.
- Some of the things (such as threats) need to be kept
- The timelines need to be adjusted and objectives added.
- We will move forward by revisiting the tasks, objectives and timelines at the next meeting.

Next meeting will most likely be in Pierre in June. Possible dates are June 7th & 8th or June 14th & 15th. We will check into space and email everyone with that information.

PLANS and Family Support Council

- Welcome and Introductions

Family Support Council Presentation

- It appears that PLANS and Family Support are looking at the same goals.
- There are a total of 15 members when the whole group can attend meetings.
- Formally began in 1988.
- In 1991 strategic planning ended and family support began.
- 1993 – Milbank, Watertown and Sioux Falls became part of statewide family support programs.
- 1994 – Gov Miller signed bill that gave funding to family support council.
- 1995 – Formalized mission statement.
- 1998 - Included the Yankton-Vermillion area, Rapid City, Brookings and a second program in Sioux Falls.
- 1999 - Included Rosebud and Pine Ridge.
- 1999 - Home and Community Based Services waiver expanded.
- HCBS family waiver was renewed for another five years.
- Great outcomes have come about due to the family support council.



PLANS Presentation (refer to handout)

- The workgroup started 1 ½ years ago.
- Two groups had a hand in starting PLANS, which are GRDDSS in Milbank/Sisseton and Pathways in Sioux Falls.
- DD was awarded a planning grant called Family Support 360 in Fall 2003.
- Choice and Control are key words in PLANS.
- The statewide workgroup was appointed by Wanda Seiler.
- In the first year, attended monthly meetings with GRDDSS in the northeast part of the state.
- Looked at data from the NCI surveys and public forums regarding needs and satisfaction.
- Workgroup recommended modeling family support program but focus on the adults.
- Five year implementation plan was approved Fall 2004.
- Will develop local programs to serve 40 people in each program.
- PLANS Coordinator will provide service coordination.
- Funds to be used for services are flexible yet limited.
- The southeast program is up and running and the northeast will be started in the near future.

- We are planning for coverage for the state and continuing to look at service delivery models for those accessing HCBS funding.
- We are also planning for a waiver or amendment so the services are available once the grant funding ends.

Group Discussion

- If we are successful in a waiver, it will add funds.
- Trish Dorn – How do you see it playing out if the services are right for a person – this is the kind of life that is appropriate and fits into Medicaid's criteria? Answer: Wouldn't recommend anyone giving up HCBS funding at this time to go to the PLANS funding, because PLANS funding at this time is less than what an individual can otherwise get through a typical HCBS funding.
- State statute says funds can only go to non-profit adjustment training center.
- Family support council foresees themselves playing a big advisory role for the PLANS group.
- Three people are part of both the PLANS group and the Family Support Council and it would be nice if in the future these three people could report to the PLANS group and Family Support Council and perhaps hold an occasional meeting in conjunction.
- Everyone is always welcome to attend either meeting.

Travis: Could we get a copy of each other's minutes?

Answer: Yes. And it is possible that the minutes could be addressed at the Family Support Council meeting and brought back to the PLANS meeting.